

**08** (S)

# MS Essentials

For people living with MS

## Getting the best from social work in Scotland

This guide will help you find your way around community care assessments and services to get the social care you need. It takes you through the most common steps and offers advice on what you are entitled to and what you need to know.

- If you are affected by MS to the extent that it affects your daily life, you are entitled to have your social care needs **assessed**.
- This is an **entitlement** – not a favour.
- Any informal carer (partner, family member or friend who provides you with *regular and substantial* care and practical support) is also entitled to a Carer's Assessment.
- Keep a record of your contacts and communications with social services – build it up as you go along. You will find it very useful to refer to later.

### This guide is divided into four parts

- A** The step-by-step guide to assessment [page 2](#)
- B** Your self-assessment checklist to use **before** the assessment by social work department [page 10](#)
- C** 'Quick Guides' to
  - Eligibility criteria
  - Direct payments
  - Complaints scheme
  - Getting advice and help [page 12](#)
- D** How to set up and keep your own record of all your contacts with social services [page 16](#)

\* This publication applies to social work in Scotland. The law is different in England, Wales and Northern Ireland but most of the general principles will apply.

# Part A

## Step-by-step guide

**Step 1: Find out the contact details of your council's social work department.** Local Authorities have different structures and there may not be a separate Social Work Department in your Council. If in doubt, contact your Council Headquarters for advice.

You can find this in a local paper, telephone directory, library, your GP's surgery or by the internet. Once you have found them, write down the contact details so that they are easy to refer to.

Contact details	
Name of my council	
Telephone number for the team for adults with physical disabilities	
The team's address	
The email address (if you use email, this may be useful)	

### Step 2: Ask to have your community care needs assessed

The first time you make contact it is likely that you will speak to the Duty Social Worker. Some social work departments may have special teams dealing with neurological conditions. If uncertain, ask for the social services team for physical and sensory disability.

Tell them that MS affects your **daily living** and that you would like to have your **needs assessed**. If you receive a lot of support from a carer, ask for a **Carer's Assessment** too.

Make a record of	
The date when you asked for a needs assessment	
The name of the person you asked	
How you did it (letter, phone call, email)	

‘Prepare for the assessment using the checklist in Part B to make sure you cover everything needed. You should use this before the assessment visit.’

### Your entitlement to an assessment of your community care needs’

Under the Social Work (Scotland) Act 1968, local authorities are responsible for assessing the needs of people who may need care services to enable them to carry on living at home.

### About Carer’s Assessments

The Community Care and Health (Scotland) Act 2002 ensures that carers needs are met more directly. The fundamental principle underlying this legislation is that carers should be recognised and treated as **key partners in providing care**. In addition the legislation recognises that adequate **resources** are needed to enable carers to continue to give care.

Adult carers providing regular and substantial care and young carers under 16 are entitled to an assessment of their ability to care independent of any assessment of the person they care for. Local Authorities have a duty to inform eligible carers of their right to an assessment and to take account of the views of the person in need and their carer before deciding what services to provide.

Under the 2002 Act, the Scottish Executive has the power to require that NHS Boards have in place Carer Information Strategies. These are expected to be in place from Summer 2006.

Community care assessments are not things done **to** you but things done **with you**. Be ready to play an active part as far as you can. It’s **your** assessment. To make the best contribution to your assessment you will need to prepare for it.

### Step 3: Prepare for the assessment

Use the checklist in Part B to make sure you cover everything needed. You should use this before the assessment visit.

It is very important to prepare for your needs assessment. Think about the day-to-day impact of MS on your life and the various ways it affects you. Write down the names and contact details of the health care staff that social work should consult with as part of the assessment. The most important step is for you to carefully identify all those aspects of every day life you need help with. The checklist on page 10 should help you get started and covers most of the aspects of everyday life that may be affected by disability. If you are affected by MS fatigue be sure to consider its impact and be sure to explain it to the social worker.

‘Take the assessment in your stride, know what you want to say, have your facts and views ready, keep your own record.’

Social workers – even those specialising in adult disability – may not know much about MS. You can suggest that they view the professionals pages on the MS Society Scotland website or contact the MS Society Scotland Information Team (see back cover for contact details).

#### Step 4: The assessment

When it comes to the assessment, know what you want to say, have your facts and views ready and keep your own record of what is said and done.

Your needs assessment will usually be carried out by a qualified social worker who may be called a ‘care manager’. It will usually take place at your home.

Be sure to get the person’s name, business address and telephone number (if you use email, ask for that too).

Each social work department uses its own model of assessment, but the purpose is the same – to find out about your needs through **asking you questions**, **observing you** and **gathering information from others** (usually health professionals, and only with your permission).

#### Needs to be considered

The assessment must consider all your needs, including

- personal
- social
- health
- accommodation
- finance
- leisure
- transport, mobility and access
- psychological
- emotional
- cultural

Be sure to ask as many questions as you want. It will help to write these down before the assessment visit. You are entitled to have answers in writing. Add these to the record of all your contacts with social work. It is a good idea to keep them all in a ring-binder or folder.

'You must be given a written copy of the result of your assessment.'

### Step 5: Getting the result of your assessment

You are entitled to a copy of the final assessment along with formal notice of whether your needs require a service and – if so – what is being offered. This is often called the 'care plan'.

If there has been a Carer's Assessment, a copy of that is sent too.

If you meet the local **eligibility criteria** and are offered a service you should also be told about **Direct Payments**.

To find out more about eligibility criteria go to Part C;  
To find out more about Direct Payments go to page 8.

#### Eligibility criteria and charging policies

Councils set **eligibility criteria** to decide who qualifies for services. They also have different **charging policies**. Councils must set these within national guidance but are free to decide the local content of both. Convention of Scottish Local Authorities (CoSLA) in consultation with the Scottish Executive issued guidance in May 2002 on charging for non-residential services.

They are required to explain both of these to you. If you have questions, **ask**, and where possible **enter the answers in your log** (see page 16).

There are many sources of advice and help, including organisations run by and for people with disabilities. Consider asking for advice from such independent groups if you need help understanding your council's eligibility criteria or charging policy. Contact details are given on page 17.

‘You will be told the result of your assessment. This should be done in writing. You have a range of options to consider. Don’t be afraid to seek advice and to ask questions.’

### Step 6: Decision time

You will be told the result of your assessment. This should be done in writing. You have a range of options to consider.

Don’t be afraid to seek advice and to ask questions.

You can ask:

- the social worker
- your MS Society branch (listed in the phone book)
- a local Disability Resource Centre or Independent Living Centre
- the MS Society Helpline (see back cover)
- another advice service such as Citizens Advice Bureau (CAB)
- The Princess Royal Trust for Carers can provide advice and support in relation to carers assessments.

Take time to consider the options.

#### **If you have been told that you do not meet the threshold for any service:**

- make sure you understand the reasons. If these are not clear ask for clarification and ask for it in writing.
- consider taking advice from an independent source – your MS Society branch, a Disability Resource Centre, Independent Living Centre, CAB or Law Centre.
- call the MS Society Helpline – they can’t advocate on your behalf but can talk you through the options.
- you can ask social work to review the decision, and you can argue that you meet their eligibility criteria if you believe you do. You can also argue that the assessment was in some way incomplete.

#### **Do I ask social work to review their decision?**

You can ask social work to review their decision. It is best to do this in writing and to keep a record of your request. You will need to show why you think the assessment was incomplete in some way, or that you believe they failed to take proper account of your situation.

#### **Do I complain?**

If you believe that the assessment has got it wrong consider making a complaint. All social work departments have a complaints system. Don’t worry that people will take it personally – you are complaining about the process and the decision, and asking for it to be reviewed.

## About complaints schemes

All social work departments are required to operate a **complaints scheme**. Usually there are three stages, first a local review and attempt at resolution. Often this is enough. Or it can go on to 'Stage 2' where the matter is formally investigated. If you are still dissatisfied with the result of the investigation you can request that the decision is reviewed. This review will usually be conducted by a Committee comprising elected members (Councillors) and may be chaired by an external person.

Do not feel uncomfortable about using the complaints system – make it clear that your complaint is about a process or decision and not about personalities. It is possible to maintain cordial and professional links with individual staff and it is always worth making the effort to do that.

Making a complaint ensures that the matter is reviewed. The best social work departments regard the complaints system as something that is positive – it can help them put things right and it allows them to learn about how they might improve their service.

You will not be penalised in any way for making a complaint.

### **Remember:**

- keep any complaint focused on the issues
- take advice from an independent source
- provide specific reasons
- remain polite and courteous

### **How do I complain?**

Contact your social work department and tell them you want to make a complaint. Social Work Departments are required to have a complaints procedure and some may have a designated complaints officer. Your local office should be able to help you, but if not, contact your Council Headquarters and ask them to send you a copy of the Complaints Policy and procedure. This will usually include a form for you to record your complaint.

### **If your assessment results in a service being offered:**

- ask for clarification if needed
- decide if you are happy with the result. If you are unhappy with the decision or the process that led to it, you can use the complaints system to challenge it and have the result reviewed (see above)

**You now have to decide whether you want social services to organise and provide the care services you are being offered or whether you would like to organise them yourself. A scheme called 'Direct Payments' means that you can ask for the money rather than the services to be given to you and for you to arrange the services yourself.**

### **Direct Payments**

Direct Payments allow social services to pass to you the monetary value of the care services they assess you as needing. This then allows you to choose and arrange those services in a way that provides you with flexibility, choice and control.

Direct Payments are not suitable for everybody. Some people do not want the work involved in making the practical arrangements or handling the paperwork. Other people have found that Direct Payments have transformed their lives.

You should consider talking with other people in your area who use Direct Payments. Your MS Society branch or other local disability groups should be able to put you in touch.

If you choose Direct Payments you must make sure you handle the money in accordance with the local terms. It is not as difficult as it sounds, and you can get help to purchase care services from your own or neighbouring local authorities.

See the 'Direct Payments' section in Part C.

### **History of Direct Payments**

The Community Care (Direct Payments) Act 1996 **allowed** local authorities to make direct payments to disabled people with community care needs. However they were not **required** to offer people direct payments. The Community Care and Health (Scotland) Act 2002 changed this and since June 2003 it became a duty for local authorities in Scotland to offer direct payments to disabled people who require community care services. From 1st April 2005, the Scottish Executive extended the duty to offer direct payments to all people over 65 years assessed as needing support.

'Your council can arrange a care package for you, or you can arrange your care yourself using Direct Payments.'

## Step 7: Getting social care services

**Any care package you have will be reviewed** from time to time by your local social work department. You can also request a review if your needs change. When a review is planned you should prepare for it – using the checklist on page 10 is a good starting point.

### Remember:

- not everyone will be assessed as needing social care – it will depend on your assessed needs and the thresholds (eligibility criteria) used by your local council.
- if you are assessed as needing services, you are likely to be financially assessed to see what contribution, if any, you are thought to be able to make.
- at the time that you are assessed it may be that MS is not affecting you to any great degree. Don't let that put you off as the process of assessment means that essential information is gathered by social services should your need for social care change at a later date.

### Free Personal and Nursing Care

The Community Care and Health (Scotland) Act 2002 which came into effect on 1st July 2002, introduced arrangements to provide free personal care for people over 65 provided they are assessed as needing it.

Local Authorities are no longer able to charge for personal care provided for people aged 65 and over in their own homes. Those aged 65 and over living in care homes, who would otherwise pay their own fees, receive £145 a week towards personal care and a further £65 if nursing care is also required. People under 65 can also receive £65 towards nursing care.

Personal care includes: personal assistance – eg help with dressing; personal hygiene; continence management; food and diet; problems of immobility as they affect personal care and moving around indoors; behaviour management; simple treatments eg help with eye drops.

The specific amount of free care you will receive is determined by a local authority assessment and there is no set limit to the amount they can provide.

# Part B

## What help do I need?

### A checklist

This self-assessment checklist should be used before your needs assessment. It will help you identify your social care needs and those of any carer. During your assessment you must highlight the areas in which your disability requires social care support.

<b>My needs – personal, domestic, social</b>			
<b>This checklist does not cover everything but it should help you identify the areas in which you need some kind of help. Talk it over with any carer, partner or friend – their view will be helpful as you work through the list.</b>	<b>Can I do this without help?</b>	<b>Can I do this only with some help?</b>	<b>Can I do this only with a great deal of help?</b>
<b>Getting up</b>			
I can move in and out of bed...			
I can take a bath or shower...			
I can do my hair, clean my teeth...			
I can shave...			
I can get my clothes and get completely dressed...			
I can get to the toilet, use it and attend to myself...			
<b>Preparing meals</b>			
I can shop for my food and other routine needs...			
I can make myself drinks during the day...			
I can prepare a cooked meal (if I have the ingredients)...			
<b>Maintaining my home</b>			
I can care for and wash my clothes...			
I can do routine housework (dusting, vacuuming, general cleaning)...			
<b>Getting out, getting to work</b>			
I can leave the house and get about...			
I can travel to my place of work...			
I am able to maintain my social contacts (visiting friends, going to a pub or restaurant, attending films and other events)...			

## Fatigue

MS can lead to serious physical fatigue. This affects some people at particular times of the day and causes overwhelming tiredness. Other people are affected in particular muscle groups. Remember that fatigue will be invisible to the assessing social worker unless you tell them about it.

**The areas covered on the previous page deal with some of the main aspects of daily living. Depending on your own situation you may need to go into more detail, in readiness for your needs assessment by social work. If you do, the following headings may be of further use:**

Personal needs	Domestic needs	Social needs
washing face	help with eating	help with communication
washing upper body	getting prescriptions	studying at home
washing lower body	laying tables	pursuing a hobby
washing hair	making/ changing beds	using the computer
menstrual hygiene	washing dishes	using TV and radio
trimming nails	laundry	managing bills and money
foot care	ironing	household paper work
skin care	mending clothes	going to meetings
ear care	gardening	opportunities to meet people, develop friendships, contribute to your community
brushing hair	house repairs	pursuing volunteer work
positioning in wheelchair	vehicle maintenance	cultural needs (arising from race or faith for example)
help with exercises	wheelchair maintenance	
	child care	
	looking after pets	

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## Part C

### Quick guides

This section gives a quick guide to some key subjects. Your local council will have more information – ask them to send it to you. You can also obtain more information from a wide variety of sources such as:

- Internet (if you have access)
- Local Disability Resource Centre
- Libraries
- MS Society Helpline
- Local MS Society branch
- Local Independent Living Centre
- Citizens Advice Bureau (CAB)
- Princess Royal Trust for Carers

It really does pay to take independent advice. MS Society Scotland Information Team and Independent Living Centres can provide details of local independent advice sources, advocacy organisations and disability support groups. (see contact details on pages 17 and back cover).

## Eligibility criteria and charging policies

Each social work department sets out its **eligibility criteria** – the thresholds below, which they won't provide services and above which they will.

Your council's eligibility criteria is a public document and you should ask for a copy. Some councils publish it on their website.

In Scotland, councils will also have local **charging policies**. These set out the financial contribution you would be asked to make if you are assessed as needing services. Ask for details from your council and seek advice from a local independent source.

The Convention of Scottish Local Authorities (CoSLA) provides guidance for local authorities on charging for services. Although voluntary, the guidance is agreed with the Scottish Executive and implementation is monitored by CoSLA. The Scottish Executive is keen to encourage fairer and more consistent eligibility and charging policies across Scotland.

## Direct Payments

If the assessment shows that you are entitled to social care services (such as personal and domestic homecare, day care, meals, respite/short breaks) you can choose to have social work arrange those or you can choose to receive the cash value and arrange the services yourself.

**Direct Payments** were made possible in the UK by a new Act in 1996. Take-up has been slow – partly because there was not enough information or support for those interested in this option.

Direct Payments will involve some extra work for you but the benefits include flexibility and being in control. For some people this has changed their lives, giving them self-confidence, greater control over their lives and new choices and opportunities.

**Take time to think this through and be sure to talk to people already getting Direct Payments.**

These are the pros and cons some people have identified:

<b>Positives about Direct Payments</b>
It gives you flexibility
You can take control and make decisions
You choose your own Personal Assistant(s)

<b>Negatives about Direct Payments</b>
You have to manage the process and keep records
Some councils offer poor levels of support
You employ your Personal Assistant(s) and so you become an 'employer'

The MS Society Scotland website also has information on Direct Payments and local support organisations (see back cover).

The government believes that Direct Payments can deliver flexibility and control to many disabled people. It is committed to improving the scheme and the range of support and advice available to those choosing this route. The MS Society fully supports this position and campaigns for the widest possible range of choices for those receiving social care services.

## Making a complaint

All social work departments are required to have a complaints procedure and usually a designated senior manager to deal with complaints. If you are not happy with the service you get or a decision that has been made, raise it with the staff involved. If that does not bring about change, **use the complaints procedure**.

See Step 6 (page 6) on how to do this.

The complaints procedure has a number of different stages. If you remain unhappy at the result of any stage you can take it further to the next one. The council will explain each of these to you. If you are still unhappy at the result, you can take your complaint to The Scottish Public Services Ombudsman who will consider Complaints about:

- administrative failure;
- failure to provide a service;
- failure in a service provided;

in health service and local authority services (See page 19 for contact details).

Social care services can be complicated, but they are not impossible to understand – remember:

- never be afraid to ask for help. There are many sources of advice and information. Your local MS Society branch and the MS Society Helpline are good places to start.
- keep a detailed record of dates, events and communications (letters, phone calls, emails).
- it's **your** life. Take responsibility for asking for what you need – you'll find a great deal of help is available from a wide range of sources.

## Part D Keeping a log

**It really makes sense to keep a log of all your contacts with social work department, and other key events.**

Use a notebook, ring-binder or folder – or if you enjoy using a computer, create a log on your word processor. You will find it invaluable when reviewing services, mapping changes in your needs, or if you should wish to make a complaint.

**Get into the habit of recording!** If you are unable to do this, perhaps a carer could help. Some people record entries into a dictaphone, which get typed up later.

Here is a suggested format:

- Have a column which shows the date of the entry and what kind of event it was – for example, ‘telephone’, ‘visit’, ‘letter’, ‘email’.
- Then make a short record of what happened – what was said, who said it. There is an art to making reliable, concise records. Just practise it! The aim is to create a running record you can refer back to later.
- You may want to have a third column to mark up things you don’t want to forget and which may need following up.

Date and event	Notes	Things to follow up
Telephone call to Mary Smith, Care Manager 17 Dec 2005	Told Mary that I was waiting for the copy of my Assessment – it had not come. She said she was sorry for the delay and that it would be sent tomorrow.	If it does not arrive, call again (this is the second time there have been delays).

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## Sources of help

### **Carers Scotland**

A carer-led organisation providing information, training and campaigning for carers' rights

91 Mitchell Street  
Glasgow G1 3LN  
Telephone 0141 221 9141  
Carers Line 0808 808 7777  
[www.carerscotland.org](http://www.carerscotland.org)

### **Scottish Commission for the Regulation of Care (Care Commission)**

Independent Regulator of care services in Scotland which registers, inspects and publishes reports on services and operates through a network of Regional Offices

The Care Commission  
Compass House  
11 Riverside Drive  
Dundee DD1 4NY  
Telephone 01382 207100  
Locall 0845 603 0890  
[www.carecommission.com](http://www.carecommission.com)

### **Law Centres**

A number of community based law centres around Scotland provide advice and legal representation on community care, disability rights and related topics. For more information: contact MS Society Scotland or your local CAB or independent advice centre

### **Lothian Centre for Integrated Living**

Led by people with a disability, the Centre provides a range of services including: training, information, advocacy, support and assistance. Also provides specific support to young people 16-25.

Norton Park  
57 Albion Road  
Edinburgh EH7 5QY  
Telephone 0131 475 2350  
[www.lothiancil.org.uk](http://www.lothiancil.org.uk)

### **Glasgow Centre for Inclusive Living**

Led by people with a disability, the Centre provides a range of services including: training, information, advocacy, support and assistance. Also provides specific support to young people 16-25.

117 Brook Street  
Glasgow G40 3AP  
Telephone 0141 550 4455  
[www.gcil.org.uk](http://www.gcil.org.uk)

### **Scottish Personal Assistants Employers Network (SPAEN)**

Peer support, advice, training and advocacy; information on best practice of employing personal assistants; representation and policy development

Unit 9  
Motherwell Business Centre  
130 Coursington Road  
Motherwell ML1 1PR  
Telephone 01698 250280  
[www.spaen.co.uk](http://www.spaen.co.uk)

### **Disablement Income Group Scotland (DIG)**

Free information and advice on benefits for people with a disability and carers in Scotland. Provides telephone service.

5 Quayside Street  
Edinburgh EH6 6EJ  
Telephone 0131 555 2811

### **Citizens Advice Bureau**

Offers free, local confidential, impartial and independent advice through network of independent bureaux across Scotland. Home visits, telephone and online advice provided.

To find your nearest bureaux Contact:

Citizens Advice Scotland  
Spectrum House  
2 Powderhall Road  
Edinburgh EH7 4GB  
Telephone 0131 550 1000  
[www.Cas.org.uk](http://www.Cas.org.uk)  
Online Advice Service [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

### **Scottish Executive Health Department**

St Andrew's House  
Regent Road  
Edinburgh EH1 3DG  
Telephone 0131 556 8400  
[www.scotland.gov.uk](http://www.scotland.gov.uk)

## **The Princess Royal Trust for Carers in Scotland**

A Network of thirty six locally managed Carers centres providing support, information and advice to carers.

Campbell House  
215 Campbell Street  
Glasgow G2 4TT  
Telephone 0141 221 5066  
[www.carers.org](http://www.carers.org)

## **Update**

The National Disability Information Service in Scotland.  
Provides a wide range of information-related services;  
Runs a Helpline providing confidential generalist and rights information to organisations and individuals.

Beaverhall Road  
Edinburgh  
EH7 4JE  
Telephone 0131 558 5200  
[www.update.org.uk](http://www.update.org.uk)

## **Scottish Public Services Ombudsman**

Freepost EH641  
Edinburgh  
EH3 0BR  
Telephone 0870 0115378  
[www.scottishombudsman.org.uk](http://www.scottishombudsman.org.uk)

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Disclaimer: we have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed. Suggestions for improvement in future editions are welcomed. Please send them to [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

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With thanks to  
Roy Webb of NCIL  
The Disability Law Service  
The Scottish Executive Health Department  
CoSLA

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Printed February 2006

## Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and around 85,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS Helpline, grants for home adaptations and mobility aids, education and training, specialist MS nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds over 50 vital MS research projects in the UK and makes an overall financial commitment of £12 million towards research: each year £2 million is given to new projects.

Membership is open to people with MS, their families, friends and supporters.

You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer.

### Contact information

MS Society, Scotland  
Ratho Park, 88 Glasgow Road, Ratho Station  
Newbridge EH28 8PP  
Telephone 0131 335 4050

MS Society, UK  
372 Edgware Road, London NW2 6ND  
Telephone 020 8438 0700

MS Society, Northern Ireland  
34 Annadale Avenue, Belfast BT7 3JJ  
Telephone 028 9080 2802

National MS Helpline  
Freephone 0808 800 8000 (Weekdays, 9am-9pm)

[www.mssocietyscotland.org.uk](http://www.mssocietyscotland.org.uk)  
[enquiries@mssocietyscotland.org.uk](mailto:enquiries@mssocietyscotland.org.uk)

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